

Members:

Rep. Vanessa Summers, Chair  
Rep. Mark Lytle  
Rep. Robert Alderman  
Rep. Cleo Duncan  
Sen. Richard Worman  
Sen. Kent Adams  
Sen. Allie Craycraft  
Sen. Joseph O'Day



Lay Members:

Hugh Beebe  
Capt. Michael Carmin  
Nan Daley  
Donna Ott  
Herbert Grulke  
Becky Zaseck

## **COMMISSION ON AUTISM**

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Authority: IC 12-11-7

### **MEETING MINUTES**

Meeting Date: October 21, 1998  
Meeting Time: 10:30 A.M.  
Meeting Place: State House, 200 W. Washington St., Room 156-B  
Meeting City: Indianapolis, Indiana  
Meeting Number: 5

Members Present: Rep. Vanessa Summers, Chair; Rep. Robert Alderman; Rep. Cleo Duncan; Sen. Richard Worman; Sen. Kent Adams; Hugh Beebe; Nan Daley; Donna Ott; Herbert Grulke; Becky Zaseck.

Members Absent: Rep. Mark Lytle; Sen. Allie Craycraft; Sen. Joseph O'Day; Capt. Michael Carmin.

### **CALL TO ORDER AND OPENING REMARKS**

Rep. Summers called the meeting to order at 11:30 a.m. She stated that this was the final meeting of the Commission for the 1998 interim session.

### **MEETING MINUTES**

Rep. Summers told the Commission members that Sue Lindborg of Cristole, Inc. and Lauren Polite of FSSA requested several minor technical corrections to the minutes from the meeting on September 21, 1998. Susan Preble, Lead Staff, distributed a handout of the proposed revisions and explained the changes.<sup>1</sup> The Commission adopted a motion to amend the minutes.

### **TESTIMONY ON INSURANCE COVERAGE FOR PERSONS WITH AUTISM**

**Dan Rives, Director of University Benefits for Indiana University**, thanked the Commission for the opportunity to testify, and explained that he was unable to attend previous meetings due to scheduling conflicts. Mr. Rives testified that there are a total of nine different health care plans available to Indiana University employees of all eight campuses. He stated that the health care plans usually cover expenses associated with diagnostic services for children with autism, and that costs resulting from illness and injuries are also covered as long as they are considered "medically necessary" services. In response to

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<sup>1</sup>A copy of the handout is on file at the Legislative Information Center, Room 230, State House, Indianapolis, Indiana. The telephone number of the Legislative Information Center is (317) 232-9856, and the mailing address is 200 West Washington Street, Suite 301, Indianapolis, Indiana 46204-2789.

questions from the Commission members, Mr. Rives confirmed that although the plans differ with regard to co-payments, deductibles, and group plans, none of the plans cover interventions, treatments, prescription drugs and other services specifically designed to treat persons with autism. Nan Daley responded that although autism is a lifelong developmental disability, it can be helped with proper intervention and therapies.

Rep. Summers asked if Mr. Rives could recommend riders that families could use, since Indiana University's employees with autistic children are not being served by any health plan. Mr. Rives responded that he is willing to explore the feasibility of such an option. Rep. Alderman noted that while Indiana University receives research grant funds to determine how pharmaceuticals affect autism, the University's own health plans do not cover drugs for autism.

Mr. Rives reported that awareness is developing with regard to autism and the treatments that are available. Ms. Daley stated that intervention for autistic individuals has a proven track record, but despite a great deal of documentation on the positive effects of treatments, families still do not have access to such intervention.

Mr. Rives explained that autism is listed as an exclusion for coverage in all the health plans the University offers. He stated that the exclusion will eventually be eliminated for some treatments, but that one difficulty is that many of the therapies do not require skilled health care practitioners. Mr. Grulke stated that the exclusion is due to the fact that the medical community considers autism to be an incurable developmental disability. He stated that employers can ask insurance plans for unlimited exclusions as long as they are willing to pay for it.

Mr. Beebe asked if Indiana University offers a plan with a higher co-payment for those employees who are willing to pay for additional coverage for autism. Mr. Rives explained that the plans are not distinguished by diagnosis.

Mr. Rives testified that \$37 million of the University's budget is used to pay its part of the premiums for the various plans. Sen. Adams stated that if any state funds are used to pay some portion of the premium, the University has an opportunity to be a leader in this area and not a follower. Mr. Rives agreed and assured the Commission that he will explore the possibility of covering some treatments for autism. Sen. Worman commented that the State of Indiana should also consider expanding insurance coverage for autism for state employees.

Penny Githens distributed a handout and testified that other incurable neurological conditions, like cerebral palsy, are not excluded in most health plans.<sup>2</sup> She stated that with medication and intervention before the age of six, autistic children can move toward normalcy. Ms. Githens cited a mental health study that determined the cost to be \$4 per enrollee to cover services for autism. A letter from Ruth Notter, a grandmother of an autistic child, was also distributed to the Commission members.<sup>3</sup>

## **FSSA UPDATE ON AUTISM WAIVER SLOTS**

Rep. Summers read a letter from Debra Simmons Wilson, Director of the Division of Disability, Aging & Rehabilitative Services (DDARS) with regard to the Division's progress toward filling all open slots.<sup>4</sup> Rep. Summers expressed frustration that the slots were not being filled more quickly. Sen. Worman made a motion to send a letter to FSSA expressing the Commission's disappointment and requesting that DDARS have all open slots filled by July 1, 1999. The Commission adopted the motion by consent. This policy recommendation is subject to approval by the Personnel Subcommittee of the Legislative Council per Legislative Council Resolution 1-98, Section 8.

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<sup>2</sup>A copy of Ms. Githen's handout is on file at the Legislative Information Center (see footnote 1).

<sup>3</sup>A copy of Ms. Notter's letter is on file at the Legislative Information Center (see footnote 1).

<sup>4</sup>A copy of Ms. Simmons Wilson's letter is on file at the Legislative Information Center (see footnote 1).

Lauren Polite, Legislative Liaison for the Family and Social Services Administration, testified that FSSA has sped up the eligibility process and that three more individuals had been placed in waiver slots since the Commission's last meeting on September 21. She reported that an additional five individuals are at the final stages of eligibility and should be placed in slots soon once their plans of care are approved. Ms. Polite offered to provide monthly updates to the Commission. Rep. Summers stated that she would like monthly updates and asked staff to include a request for monthly updates on the status of open waiver slots in the letter to be sent to FSSA. She asked Ms. Polite to provide a complete report on the status of the waiver slots at the Commission's first meeting of the 1999 interim session.

Kathy Smith, representing Indiana University, asked to address the Commission and reported that the University's self-funded health care plans will remove the autism exclusion.

## **CONSIDERATION OF LEGISLATIVE PROPOSALS<sup>5</sup>**

Rep. Alderman explained that PD 3526 keeps funds and accounts earmarked for developmental disability services from reverting to the general fund at the end of the fiscal year.

Herb Grulke stated that the Bureau of Developmental Disabilities is decertifying facilities without replacing them with regulated settings which results in poor quality practices. He stated that the State is moving away from its responsibility to monitor placement settings. Mr. Grulke moved to amend PD 3526 to also require the state to only place individuals in regulated settings.

The Commission adopted the motion and voted to recommend the amended PD 3526 to the General Assembly.

Rep. Alderman moved that the Commission adopt PD 3537 and not consider PD 3538. PD 3537 requires insurance coverage in the amount of \$10,000 per year for individuals with autism. PD 3538 requires insurance coverage in the amount of \$500 per month for individuals with autism.

The Commission adopted the motion and voted to recommend PD 3537 to the General Assembly.

The Commission also adopted a motion to recommend the Concurrent Resolution which encourages state insurance coverage for pervasive developmental disorders to the General Assembly. The Commission adopted a motion to forward a memo to the Governor, Department of Administration and the Personnel Department informing them of the resolution.<sup>6</sup> This policy recommendation is subject to approval by the Personnel Subcommittee of the Legislative Council per Legislative Council Resolution 1-98, Section 8.

Mr. Grulke stated he would like the Commission to consider three additional proposals for recommendation to the General Assembly. He requested that Ann Naughton, Staff Attorney, draft the following proposals: (1) an appropriation to fund an additional 50 autism waiver slots per year for two years; (2) the establishment of four additional group homes to be located in different regions of the state; and (3) require that the Bureau of Developmental Disabilities to only place individuals in certified licensed settings. He also stated that he does not want minimum standards withdrawn for those individuals already placed. In response to a question from a fellow Commission member, Mr. Grulke stated that his third proposal would not stipulate what the requirements for certification should be. Rep. Summers asked Ms. Naughton to draft the legislation and suggested that because the Commission would not be able to vote on and adopt the proposals, individual legislative members of the Commission should consider sponsoring the legislation during the 1999 legislative session.

Sue Lindborg of Cristole, Inc., asked if the Commission would endorse smaller settings of six beds or less. Mr. Grulke stated he would. Rep. Alderman disagreed and stated that the Commission should take

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<sup>5</sup>Copies of all preliminary drafts considered by the Commission are on file at the Legislative Information Center (see footnote 1).

<sup>6</sup>A draft copy of the memo is on file at the Legislative Information Center (see footnote 1).

what it can get. Rep. Summers requested that the proposal include examples of different-sized settings and their costs. Ms. Polite asked if the second and third proposals applied only to individuals with autism. Rep. Summers replied that they will apply to all eligible individuals with developmental disabilities.

## **ADJOURNMENT**

Rep. Summers thanked Sen. Worman for his many years of service to the Commission and individuals with autism. With there being no further business before the Commission, Rep. Summers thanked the members and adjourned the meeting.